Challenges in the Home for Adults Aging with Mobility Impairments

Technical Report TechSAge-TR-1702
Atlanta, GA: Georgia Institute of Technology
Rehabilitation Engineering Research Center on Technologies to Support Successful Aging with Disability (RERC TechSAge)
(www.techsage.gatech.edu)

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2017

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Suggested Citation: Fain, Brad & Farmer, Sarah. (2017). *Challenges in the home for adults aging with mobility impairments* (TechSAge-TR-1702). Atlanta, GA: Georgia Institute of

Technology, Rehabilitation Engineering Research Center on Technologies to Support Successful Aging with Disability.

Acknowledgements

This research was supported in part by a grant from the National Institute on Disability and Rehabilitation Research (Department of Education) Grant H133E130037 under the auspices of the Rehabilitation and Engineering Research Center on Technologies to Support Successful Aging with Disability (TechSAge; www.techsage.gatech.edu). The contents of this technical report were developed under a grant from the Department of Education. However, those contents do not necessarily represent the policy of the Department of Education, and you should not assume endorsement by the Federal Government.

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1. Introduction

Due to an increased life expectancy for the general public and the ramifications of the baby boom generation reaching older adulthood, individuals with long term disabilities are living longer and facing brand new challenges associated with additional age-related disabilities (Bigby, 2002). Individuals are said to have "disability with age" if they experience functional decline due to age-related declines and complications such as strokes, fall injuries, or degradation of physical ability (Yorkston et al., 2010). Those who had preexisting conditions and are reaching older adulthood are said to "age with disability." While "disability with age" has been studied for many years, less research has been done on "aging with disability."

Loss of ability due to age-related declines has been shown to lead to depression (Femia, Zarit, & Johansson, 2001). Older adults with previous disabilities often face premature aging and require assistance earlier on average (Wilson et al. 2009). Further, those aging with a disability are shown to be at a greater risk of both depression and lower cognitive function (Olaya et al., 2016). Home modification is a common practice to prevent assisted living, which may lead to reduced feelings of self-efficacy and cost large amounts of money (Unwin et al., 2009). Home modifications have been shown to increase ability to perform everyday tasks for people aging with disabilities, both soon after installation and after a six-month period of time (Petersson et al., 2009). Similarly, the use of assistive technology has been shown to increase desired functional ability in individuals with disability (Wilson et al., 2009). While AT is widely available, often those who need it may not know which devices to choose, how to install them, and how best to make use of them. Further exploration into specific routes of treatment, rehabilitation, home modifications, and assistive technology for those aging with disability is needed in order to allow these individuals to successfully age in place.

2. Purpose

Georgia Tech's HomeLab consists of a network of 600 homes distributed throughout the State of Georgia, plus the associated infrastructure needed to administer, manage, design, and execute both small- and large-scale usability, effectiveness, and efficacy studies. Participants represent a diverse cross section of older adults and represent both urban and suburban consumers. Participants in HomeLab go through a detailed induction process where information about the participants and their homes is gathered so that participants can be matched to prospective studies. HomeLab is staffed by a diverse roster of experts including those with expertise in human factors, experimental design, behavioral psychology, industrial design, data analysis, engineering, and project management.

HomeLab participants represent the diversity of the State of Georgia and include people with disabilities. As part of the TechSAge project, we were interested in HomeLab participants that were disabled prior to 50 years of age that were now aging into secondary disabilities. It was predicted that such users would face unique challenges while trying to age in place or adapt to their new challenges caused by aging. For example, someone with a lower mobility impairment may have difficulty using their wheelchair as they start to develop arthritis in their hands and shoulders. Someone who is blind may experience an increased challenge with age-related hearing loss. The abilities and assistive technologies that they are used to using may become unavailable or increasing less useful. Since many of the changes associated with aging are gradual, the changes may go unnoticed and users may be slow to make necessary changes to increase abilities. Users may gradually adapt their environments and make adjustments as needed in order to accommodate their changing abilities. We designed and executed a research

project in HomeLab to first document the challenges faced by people with primary disabilities that are aging into secondary disabilities and then to monitor them over time to look for changes in their behavior or environment. During the first visit with the participants we learned an enormous amount about how individuals were coping with changes and how they addressed their increasing inability as they aged. We visited a subset of the participants two years later asking the same questions and making the same types of observations. In this study, we compared the outcomes of the initial visit with the outcomes of a visit conducted two years later to learn about the pace of change and how individuals gradually adapted to the changes.

3. Method

3.1 Participants

Thirteen older adults (8 female) with long-term mobility impairments participated in this research study (Mage = 61.7 years, SD = 6.4; Range: 55-74). To be eligible to participate in this study, participants had to be fluent in English, age 50 or older, and have a physical impairment that limits mobility that began before age 50. All individuals participated in the initial visit conducted in 2014.

3.2 Materials

3.2.1 Interview Guide

- Demographics
- Health information
- Life Space Assessment
- Housing

- Mobility Aids
- Daily Activities Interview and Ratings
- Ideal Living situation

The interview guide, internally created to guide researchers through the semi-structured interview, covered demographics, general health, mobility in and out of the home, performance of activities of daily living, and housing.

4. Procedure

A qualitative approach allows for a deep dive to investigate this research question. Researchers visited each participant in their home and discussed the topics covered in the interview guide. Health information questions were designed to assess general health and gauge how participant health has changed since the first study. The Life-Space Assessment (Baker, Bodner, & Allman, 2003) measures the extent of movement inside and outside of the home, frequency of movement, and whether or not aids are needed. This assessment was also administered in the first study. The housing and mobility aids sections of the interview guide assess current the current state of each topic and whether anything has changed since the first study. The daily activities interview covers six activities of daily living, whether the performance of these activities have changed since the first study, whether the participant utilizes any assistive technology or aid from others, and ratings of difficulty for each. Finally, the ideal living situation portion of the interview asks participants to consider their ideal situation as they continue to age and what challenges (if any) that may prevent them from achieving this.

5. Results

5.1 Changes in Health

General health information questions gauged participants' subjective views of their overall health and how it affects their daily lives. Participants were asked how their health is overall, how they believe their health compares to other individuals their age, how satisfied they are with their health, and how often their health precludes them from doing activities they want to do. During the two-year gap between the initial visit and the follow-up visit, these indicators showed declines in health. In general, participants were less satisfied with their health, compared their health less favorably than peers, and felt their health prohibited their activities more frequently (see Figure 1, Figure 2, Figure 3, and Figure 4). Additionally, the average number of prescription medications taken daily by participants increased slightly (from M = 5.69 medications, SD = 3.2; Range: 1-14 at the initial visit to M = 5.92 medications, SD = 3.4; Range: 2-14 at the final visit), which also points toward deteriorating health.

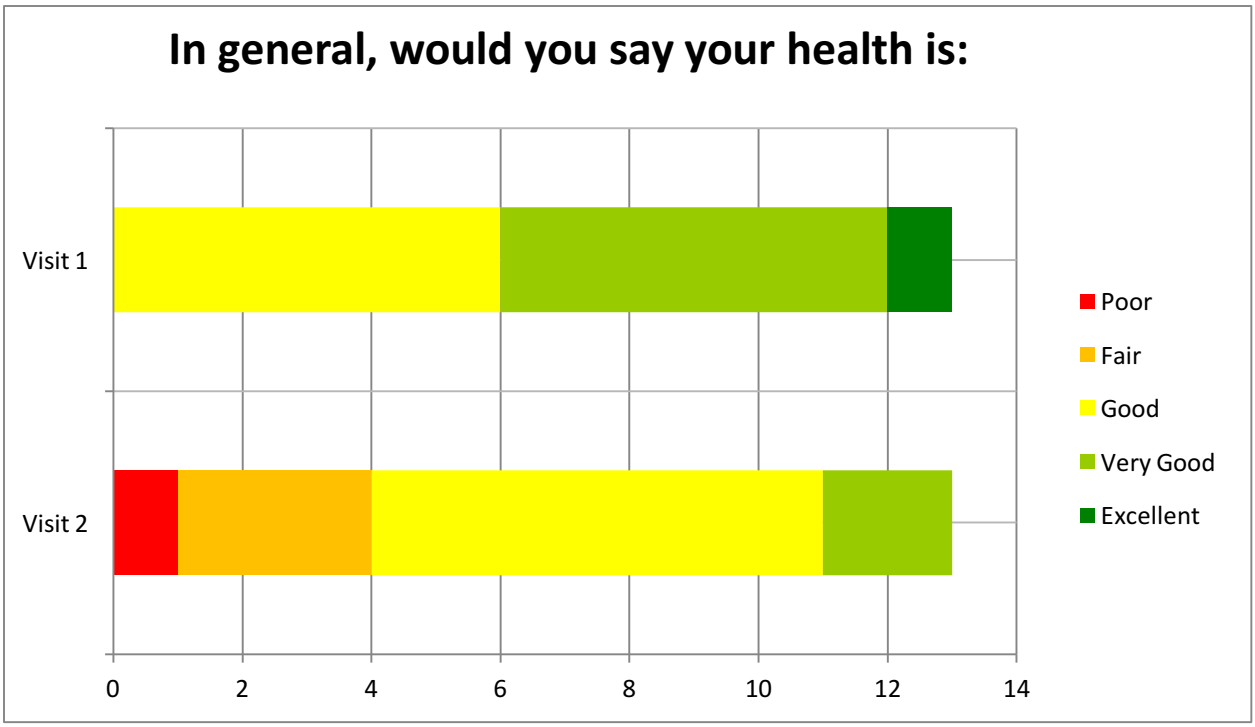

Figure 1. Change in overall health.

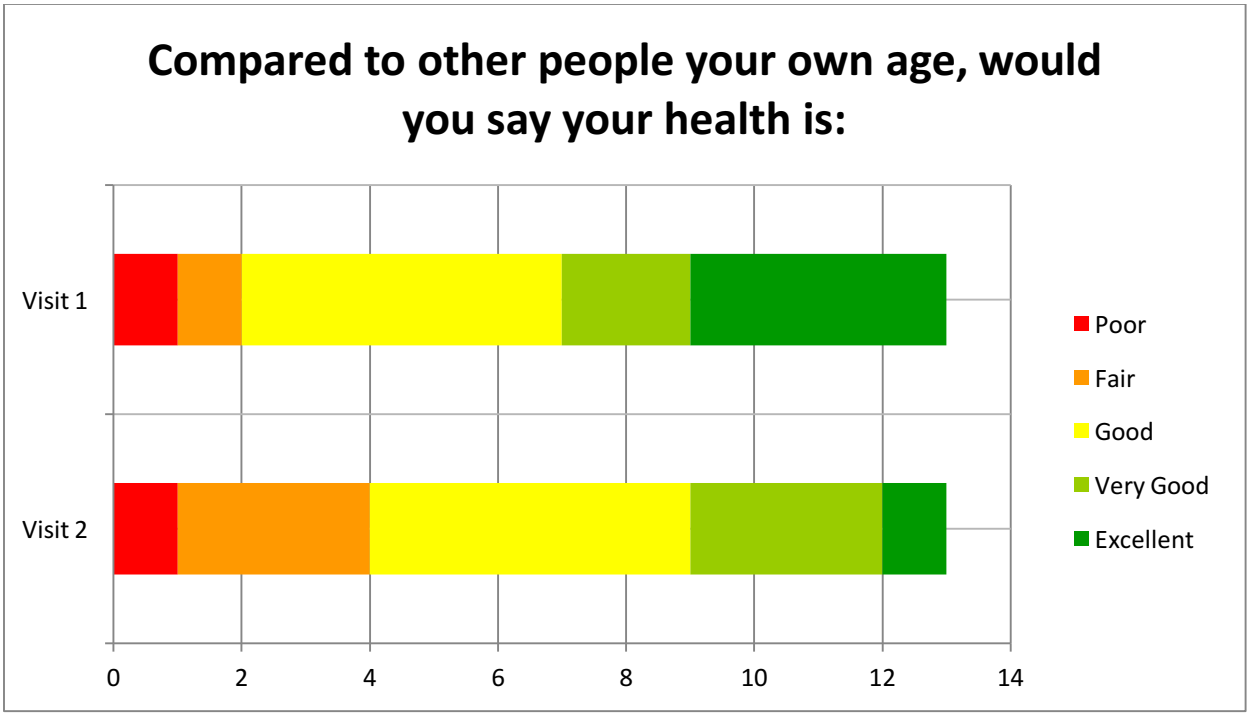

Figure 2. Changes in perception of health.

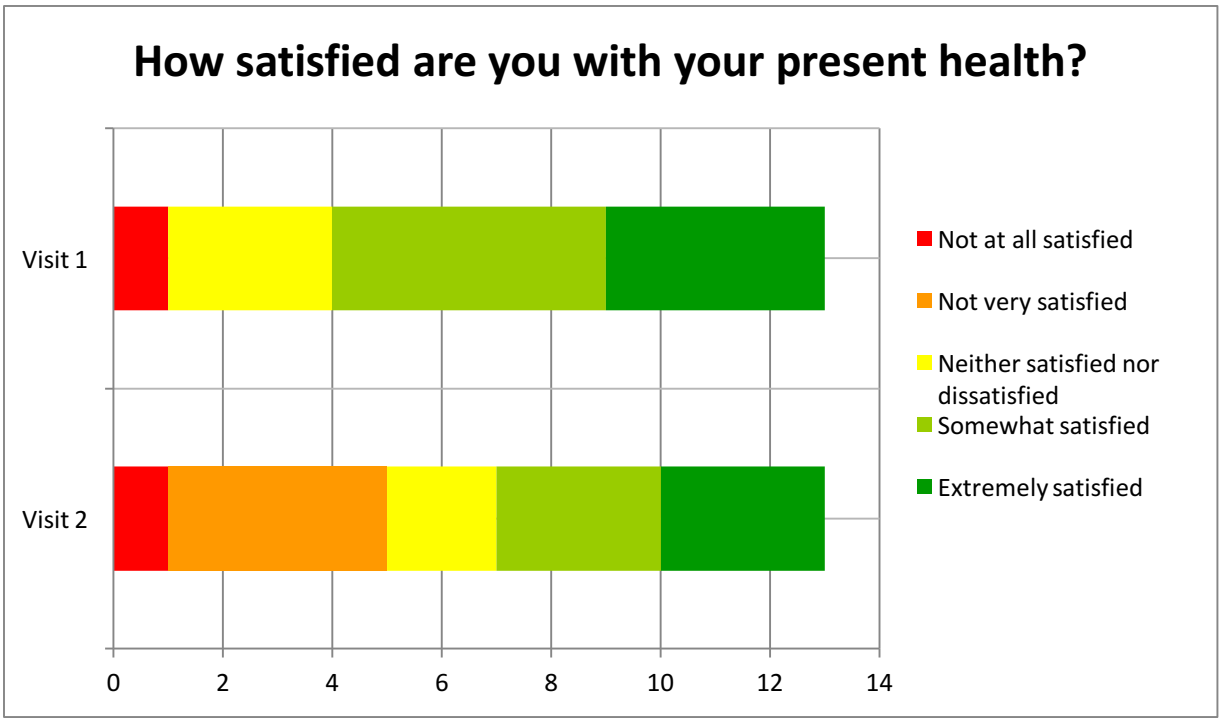

Figure 3. Changes in satisfaction with health.

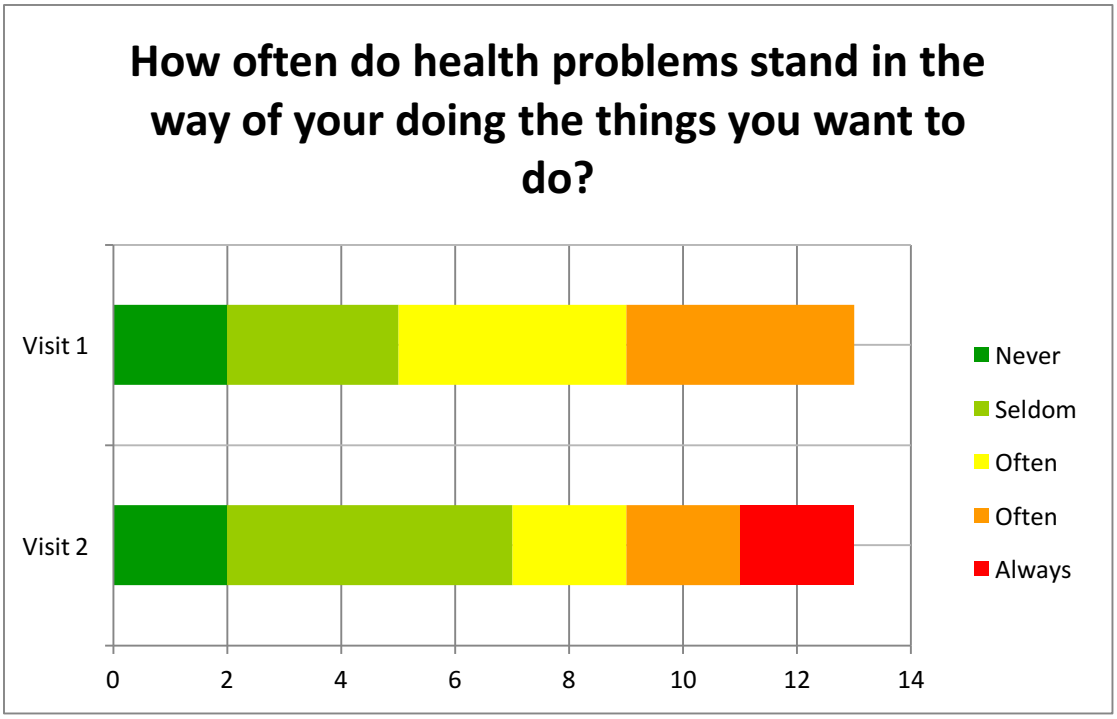

Figure 4. Changes in health prohibiting daily activities.

5.2 Changes in Routine

Participants were interviewed about their activities of daily living and how these have changed since the initial visit two years ago. Participants also completed the Life-Space Assessment (Baker, Bodner, & Allman, 2003) in order to gauge whether participants are experiencing decreased movement in and around the home. Breakdowns of the percentage of participants who reported some type of change can be seen in Table 1. Every participant made some sort of adaption since the initial assessment, whether it was behavioral (moving slower), functional (using a shower chair), or technical (buying assistive technology). While there were some improvements reported, most participants noted decreased functioning and ability to complete activities of daily living. The majority of participants stated that they had not changed their routine for these activities. More common was that participants had been required to change how they go about their routine; i.e., slowing down, adapting the environment, and/or introducing assistive technology.

	Has routine changed?	Have any changes been made to the environment to make this easier?	Have any changes been made to the environment to prevent accidents?
Bed Transfer	38.46% (5 yes /8 no)	38.46% (5 yes/8 no)	38.46% (5 yes/8 no)
Bathing	23.08% (3 yes/10 no)	38.46% (5 yes/8 no)	30.77% (4 yes/9 no)
Toileting	23.08% (3 yes/10 no)	38.46% (5 yes/8 no)	30.77% (4 yes/9 no)
Food Preparation	38.46% (5 yes/8 no)	38.46% (5 yes/8 no)	N/A
Movement around Home	15.38% (2 yes/11 no)	38.46% (5 yes/8 no)	N/A
Entering and Exiting Home	30.77% (4 yes/9 no)	38.46% (5 yes/8 no)	N/A

Table 1. Changes in activities of daily living.

5.3 Bed Transfer

Several participants reported that they require increased help to get in and out of bed. Participants reported several adaptions they have made to increase ease and safety of bed transfer. One participant stated that she turns to supervision in order to prevent accidents, while another participant uses non-slip shoes to the same end. When asked about adaptations, participants named ideal solutions to some of their problems, such as a bigger bedroom or a Hoyer lift, but often noted that these were unrealistic for them or out of their price range.

5.4 Bathing

Participants named several adaptations they have made in order to increase ease and safety of bathing. Several participants have chairs that they use in the bathing area to avoid walking or standing (see Figure 5). One participant said that she often requires assistance. Several said they used grab bars to move around, or different devices to reach objects. A participant said she attempted a bathroom renovation but that it was not successful. Most participants seemed satisfied with the solutions they had achieved in regards to bathing, though renovations were seen as desirable.

Figure 5. A shower chair makes bathing easier.

5.5 Toileting

Participants indicated that adaptions such as taller toilets or bathroom redesigns would help make the experience easier and safer. Certain participants had the seat adjusted or added a special seat to make the toilet taller (see Figure 6). One individual reported the use of a catheter and colostomy bag. Increased accessibility was called for, including a larger room for easier maneuvering and an easier way to adjust water temperature.

Figure 6. Elevated toilet seats make toileting easier.

5.6 Food Preparation

A few participants reported changes to their food preparation routine. One indicated that he simply has food prepared for him now. A few reported using a chair to navigate the kitchen area. Having important things such as food and dishes in lower areas was reported by several participants. One participant created a lower workspace so that she could prepare food from her wheelchair (see Figure 7). Some named changes they thought might make the process easier, such as food processors or maids, but said these were out of their means.

Figure 7. A lower workspace in the kitchen allows a wheelchair user to more easily engage in food preparation.

5.7 Movement Around the Home

Most participants stated they have not had many changes in this category, unless due to a move or simply going slower. However, more than a few participants indicated they can no longer access certain rooms in their house. One participant said she can no longer go up or down stairs, and that a chair lift is too expensive to obtain. In addition, several participants wished they could move to a more accessible home. Multiple participant mentioned that they don't use rugs to avoid slipping. A participant noted that she hopes to feign normality in using adaptive techniques—in other words, she wouldn't want anything to stand out as an obvious modification.

5.8 Entering and Exiting the Home

Several participants had made changes to their home to make it easier to enter or exit since the first assessment. The most common modifications were ramps and doorstops. Most participants could think of changes they wanted, such as automatic or electric doors.

5.9 Life-Space Assessment

The Life-Space Assessment (Baker, Bodner, & Allman, 2003) is designed to capture the extent of movement inside and outside the home, as well as frequency of movement and whether or not aid or assistance is required. The assessment was created to track changes of movement over time by evaluating movement within the home, directly outside the home, within the neighborhood, within the town, and outside of the town, with frequency of movement at each level and the use of a mobility aid affecting overall score. Average life-space scores decreased from the time of the initial visit (M = 44.15, SD = 18.50; range: 19-76.5) to the second visit (M = 37.46, SD = 17.11; range: 15-82.5). This indicates overall less movement with less frequency and more prevalent use of mobility aids.

5.10 Mobility Aids

Four participants reported increased use of mobility aids, new or old. Most of the increased use engendered improved mobility: gaining a new wheelchair which allows the participant to get into smaller spaces; a service dog helps another participant navigate.

5.11 Ideal Living Situation

When asked what an ideal living situation would be as they continued to age, the majority of participants stated that they wanted to stay in their current home. Some added the caveat that they would want major renovations for this home in order for it to be ideal, however. When asked if they had concerns about being able to stay in their own homes as they age, 77% of participants stated that finances were the only or primary concern. This concern is caused by the high costs of renovations, new assistive technology, and acquiring a caregiver.

6. Conclusion and Future Directions

For individuals with limitations in activities of daily living, the use of assistive technology has been shown to decrease the hours of human help needed by approximately 4.1 hours per week (Hoenig, Taylor & Sloan, 2003). Further, mobility aids and home modifications increased the feelings of independence for those aging with disabilities (Wilson et al., 2009). This research suggests that earlier interventions may be key to aging in place. While individuals with disabilities may not seek further help until their functional decline is well underway, for a smoother transition, assistive technology and other aids should be provided to the individuals at the front end of the aging process. Additionally, home modifications are most successful when installed soon after new limitations or decreased functioning begins (Petersson et al., 2009). By understanding the difficulties individuals like our participants encounter as they age, we hope the be able to better understand how to provide aid to allow them to age in place.

Research suggests that adaptive strategies may be most successful if tailored to an individual's demographics and other health characteristics; for instance, a behavioral strategy might work well for some, while environmental modifications may work better for others (Chee, 2013). Intervening early on in the progression of age-related declines and tailoring interventions to individual's characteristics and unique needs is likely to be the most successful avenue to allow those aging with a disability to age in place.

While more research is needed, anecdotally the trajectory of decline seemed greater for this population as compared to what is observed in the general HomeLab population of people without major disabilities. Timely interventions and alterations may be even more important for this population. Waiting until the need arises may be too late. Individuals may need to anticipate changes and plan accordingly to address mobility issues that may arise in the near term.

Additional research is needed but individuals might benefit from an information resource that would help them visualize changes in their functional ability as a function of age and address what they can do in order to prepare their environment adequately.

Individuals may allocate additional resources (financial and time) to compensate for decreases ability. Home modifications at the owner's expense may reduce discretionary spending. The amount of time allocated to personal hygiene may reduce time available for other activities. The difficulty of prepare for and moving about outside the home may discourage outside activities and social connectedness. One possible outcome is that individuals experience a decline in optional activities related to learning and social connectedness due to the reallocation of resources to primary activities of daily living. Future research should explore this relationship and define the role of home modifications in overall quality of life.

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